

***Elderly caregiving spouses
involved in end-of-life care:
Attending to their needs***

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Study Rationale

- **Death of a spouse is a profoundly stressful event**
- **Widowed are at increased risk for mortality and morbidity**
- **Recently bereaved spouses have higher death and suicide rates than age-matched controls**
- **Widowed have an elevated incidence of depression, somatic complaints, substance abuse, and physical health problems**

Older Couples and Careprovision

- **Death may be more readily anticipated with the elderly, but older spousal caregivers face loss of a lifelong companion**
- **Protracted & intensive caregiving may exacerbate well spouses' distress**
- **Spousal caregivers provide extensive, comprehensive care, maintain the role longer, tolerate high levels of disability**
- **Older caregivers' health status may impede care provision efforts and compound their distress**

Cancer and Older Adults

- **Cancer is an illness which usually provides forewarning of an impending death**
- **Cancer and its treatment impose stresses on patients and their spouses**
- **Number of older adults diagnosed with cancer is rising and average age at diagnosis is increasing**
- **Co-morbid conditions are more common, complicating scope and duration of caregiving**

Study Design

- **Sample consists of caregiving spouses of advanced cancer patients (n=138)**
- **Cancer patients-caregiving spouses recruited from cancer centers in urban setting**
- **Bilingual (English-Spanish) mental health clinicians conducted 2-hour, in-person interviews with caregiving spouses**

High Risk Criteria for Study Eligibility

- **Duration of terminally-ill spouse's illness**
Prolonged, six or more months by accrual
- **Well spouse's caregiving responsibilities**
Average of more than 8 hours of illness-related practical or instrumental assistance per week
- **Surviving spouse's own age**
Older adult (aged 50-80)
- **Surviving spouse's health status**
Has a chronic illness or activity-limiting health condition for six or more months at accrual

Caregiving Spouse Demographics

	Mean	(S.D.)
Age	63.6	(7.5)
Male	41%	
Parent	96%	
White	90%	
College graduate	48%	
Currently employed	49%	
Household income \$50,000+	56%	

Caregiving Situation

	Mean (S.D.)
Years since diagnosis	3.5 (3.8)
Illness increased number of household tasks performed by spouse	75%
Number of spousal caregiving tasks : ≤ 6	21%
(Checklist of 18 IADLs, ADLs)	
7-9	33%
10-12	30%
≥ 13	16%
Other family member requires spouse's care	32%

Caregiving Spouse's Social Support Resources

	Mean (S.D.)
Number of years married to ill spouse	35.8 (11.8)
Quality of marital relationship (0-24)	15.7 (3.9)
Adequacy of Social Support:	
Tangible support – Insufficient	25%
Informational support – Insufficient	25%
Emotional support – Insufficient	27%
Helping others – Insufficient	31%

Caregiving Spouse's Health Status

Reports "excellent" or "very good" health	46%
Reports health worsened since spouse's illness	30%
Had a personal injury in past year	47%
Activity-limiting health conditions:	
None	44%
One	15%
2-3	22%
4-10	19%

Caregiving Spouse's Psychological Well-being

	Mean	(S.D.)
Anticipatory Grief	36.73	(8.76)
General Severity Index (T-scores, higher=more severe)	56.60	(9.53)
Brief Symptoms Inventory Percent above cutoff for probable caseness		46%

Spousal Caregivers Experience Psychosocial Distress: Illness & Loss

- **Sadness**

"I cry now all the time."

- **Anticipatory grief**

*"I'm going to miss this man. And that's why
I'm grieving now, because he's not going to
be there."*

Spousal Caregivers Experience Psychosocial Distress: Illness & Loss

- **Anxiety and future worry**

"I'm just heartbroken, and I'm frightened of, uh, you know, being without her and being alone and, you know, I'm just -- I try to imagine what it would be like sometimes and I just -- it's hard for me to think about it."

Spousal Caregivers Experience Psychosocial Distress: Caregiving Strain

- **Caregiving is unending and encompassing**

"Sometimes I feel trapped . . . not being able to really breathe. You know, like breathe a sigh of -- whatever. That it might be over. So I can't, I can't let go yet. I can't give up, I can't."

Spousal Caregivers Experience Psychosocial Distress: Caregiving Strain

- **Futility of careprovision**

"My own fatigue is because I know where it's going. Nowhere. He's going to die. So all of this is -- nowhere."

Spousal Caregivers Experience Psychosocial Distress: Caregiving Strain

- **Emotional needs put aside**

"I've resigned myself to keeping and doing as much as I can for him. Keep the level and quality of his life at a certain peak, and live with it. And I'll deal with it and my loss and my despair...But right now I'm not going to wallow into what's coming, I have a job to do."

Regression Model: Anticipatory Grief

	B	β
Caregiving:		
Number of caregiving tasks	.66**	.25
More tasks since diagnosis	.49	.02
Health:		
# of activity limiting conditions	.78**	.22
Social Support:		
Informational support	-3.80*	-.19
Emotional support	-.55	-.03
Tangible support	-1.44	-.07
Constant (SE)	33.16*** (3.01)	
R²	.20***	(Adjusted R² .16)

+ p < .10; * p < .05; ** p < .01; *** p < .001

Regression Model: GSI

	B	β
Quality of marital relationship	-.29	-.12
Caregiving:		
Number of caregiving tasks	.41+	-.14
More tasks since diagnosis	1.35	.06
Health:		
Health worse since diagnosis	2.60	.13
# of activity limiting conditions	.69*	.18
Social Support: Informational support	-5.25**	-.24
Emotional support	-2.28	-.11
Tangible support	-.74	-.03

Constant (SE) 60.48* (4.11)**

R² .26* (Adjusted R² .21)**

+ p < .10; * p < .05; ** p < .01; * p < .001**

Logistic Regression: Caseness on BSI

	Exp(B)	Confi. Interval	
Caregiving:			
Number of caregiving tasks	1.12+	1.01	1.23
Health:			
Health worse since diagnosis	1.91	.97	3.78
Social Support:			
Informational support	.23**	.10	.50
Emotional support	.67	.28	1.60
Tangible support	1.10	.45	2.68
Constant		.95	

+ p < .10; * p < .05; ** p < .01; *** p < .001

Summary

- **Anticipatory grief significantly & directly correlated with number of spousal caregiving tasks & number of activity-limiting conditions they experienced**
- **Anticipatory grief was significantly lower among spouses reporting sufficient informational support**
- **Similar findings obtained for the General Severity Index & probable caseness on the BSI**
- **Results support the importance of sufficient informational support & caregiver physical well-being for caregivers' psychological functioning**

View Couples Living with Advanced Disease as a Unit of Care

- **Family members are not just part of the care team but are also impacted by the illness**
- **Clinical management of patients with advanced disease offers opportunity to also attend to the well-being of affected family members**
- **Important to address the informational, emotional, and practical support needs of the couple**